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ABSTRACT

A program was developed by a nurse/counselor to provide individual education and counseling for mothers having high-risk infants admitted to a Special Care Nursery after delivery. The program begins as soon after delivery as possible and evaluates the mother's skills, attitudes, beliefs, and knowledge of childrearing practices necessary for caring for her own infant. The mother's concerns, fears, and emotional stage are considered. Through the evaluative interview, the mother's areas of need and interest are noted. Subsequent visits provide information and counseling to meet the mother's individual needs. In-nursery time is available for physical contact and learning under special care. The program seems to aid mother-infant relationships and increase mothers' interest in these special infants who are often at risk for developmental delays, abuse, and failure to thrive. A trend analysis of the program points to additional concerns present for these mothers. These concerns include a sense of loss of personal identity and attention, and feelings that at-home care will be overwhelming. The patient assessment instrument is appended. (Author/RH)

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NOVA UNIVERSITY

A Program to Facilitate Care-Giving and Enhancement of the Parent-Infant Relationship for Mothers of High-Risk Infants

Practicum Submitted to the Faculty
of the Early Childhood Program
in Candidacy for the Degree of

DOCTOR OF EDUCATION

by

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Table of Contents

Chapter	Page
I. Introduction	1
The Community	1
The Site	1
The Writer	3
II. Study of the Problem	4
A. Problem Statement	4
B. Evidence of the Problem	14
C. Causes of the Problem	15
D. Related Literature	17
III. Anticipated Outcomes and Evaluation Instruments	23
A. Goals	23
B. Terminal Performance Objectives	23
C. Evaluation Instrument	25
IV. Solution Strategy	29
A. Possible Alternative Solutions	29
B. Solution Selected	32
V. Results, Conclusions, and Recommendations	39
A. Presentation and Analysis of Results	39
B. Conclusions	49
C. Recommendations	49
D. Dissemination	51
Bibliography	52
Appendices	
A. Interview Tool	59
B. Evaluation Tool	62

Abstract

A Program to Facilitate Care-Giving and Enhancement of the Parent-Infant Relationship for Mothers of High-Risk Infants.

Brenda Pulskamp, 1984: Practicum Report, Nova Univeristy Ed.D. Early Childhood Program

Descriptors: Counseling New Mothers/High-Risk Infants/ In-Hospital Program/Special Education for Parents/Support Groups

This program was developed by a nurse/counselor to provide individual education and counseling for mothers who have high-risk infants who are admitted to a Special Care Nursery after delivery. The program begins as soon after delivery as possible and evaluates the mother's skills, attitudes, beliefs, and knowledge of childrearing practices that will be necessary for giving care to her own special infant. The mother's concerns, fears, and emotional stage are considered. Through this interview, areas of special need and interest for this mother will be noted, and future visits provide information and counseling for her individual needs. In-nursery time is available for hands-on contact, and learning under special care. The program shows trends that seem to aid mother-infant relationships, and increase mother interest for these special infants who are often at risk for developmental delays, abuse, and failure to thrive.

A trend analysis of the program points to additional concerns that are often present for these mothers. These include a sense of loss of personal identity, and attention, and feelings that the at-home care will be overwhelming.

Chapter I

Introduction

In this practicum the author worked as a nurse-counselor-educator in a high-risk nursery. A parent-infant project, for new mothers of high-risk infants was developed in a community hospital in Kern County, Bakersfield, California.

The Community

The community is 300,000 but draws medically and consumerwise from areas as far away as 50 miles. Bakersfield, California is located at the southern end of the San Joaquin Valley, in central California. The major commodities are farming, cotton, oil, and some industry. There is a four-year college and a two-year college, so the socioeconomic and educational range represented is very broad. Bakersfield community has four hospitals, one being the only county hospital in a county covering 8.064 square miles.

The Site

The site of this project was at the non-profit community hospital, in Bakersfield, California. This hospital has the only maternity and nursery department in this community outside of the county hospital.

Admission to this 206 bed hospital, and in particular to the maternity department, is generally private with third party payment. Many of the staff and admitting physicians accept Medi-Cal so there is a range of socio-economic patients. Everyone admitted must have a private physician who arranges the admission. For this reason almost all of the maternity patients have had some form of pre-natal care and high-risk factors have often been identified prior to delivery.

Maternity deliveries have averaged 300 to 350 per month for the last year. The Registered Nurse staff, along with the private physician, oversee the five labor rooms and four delivery rooms. All scheduled and emergency Cesarean sections are performed in the delivery room set up for such a procedure. A new birthing unit where labor and delivery are at the same room was opened in December 1983. These are generally non-risk mothers who are discharged within 24 hours with their baby.

The nursery has several rooms, one where the admission babies are held for 72 hours, another holding room for the normal newborns, and a third for those babies being discharged. In addition, there is a Special Care Nursery (SCN), fully equipped for the high-risk or low-birth weight baby. The capacity is ten and census averages 80 percent to 90 percent. If there are extreme complications with respirations, requiring a ventilator, these babies are transported to a hospital in Fresno, California, a

community 100 miles north, for care. These same babies will often return to the local hospital for final care and weight gain before being discharged home. It is with the mothers of these resident babies in the Special Care Nursery that this project will be developed.

The Writer

The author of the project has a Bachelor of Science in Nursing Degree, with over 20 years of nursing experience which covers areas of Public Health Nursing, Pediatrics, Intensive Care and Nursing Education. Credentials also include a Master's in Special Education, with another, a Master's in Counseling, completed when the project commences. There has been experience in organizing and instructing parent groups, along with participation in filial therapy sessions for parents with infant and childhood concerns. The author has had contact with the nursing staff at Memorial Hospital both in the capacity of a faculty member for the State College, and as an employee in the Pediatric Department.

Chapter II

Study of the Problem

A. Problem Statement

The problem state that exists in the neonatal Special Care Nursery at Memorial Hospital concerns new parents of high-risk infants, along with their babies. New parents who have infants admitted to the Memorial Special Care Nursery (SCN) are often overwhelmed emotionally and drained physically. In addition, they find they are unprepared or unable to participate in the vital bonding procedure, continue emotional support, or administer the physical care required by their new infants. This situation may exist not only while in the hospital, but also when discharged.

The Bakersfield Hospital Nursery is divided into three areas. One nursery is for new babies that are under 24 hours old. These will be normal healthy infants. Nursery Two is for babies over 24 hours old who have made normal progress. Nursery Three holds the babies who are being discharged. All babies in these nurseries are returned to their mothers for feeding every four hours for a period of about 45 to 60 minutes. Parents and visitors are not permitted to the Nursery, although there is an observation window. After delivery, healthy babies may spend an hour

or so with the parents before being admitted to Nursery One. The sex, length, and identification bracelet are processed in the delivery room, while eye prophalaxis and bathing are done in the nursery.

After delivery, either the pediatrician or the obstetrician may decide to admit an infant to the SCN. The diagnosis may range from low birth weight (less than 2500 grams or 5.5 pounds), prematurity (less than 38 weeks gestational age), or physiological problems requiring treatment and care or any combination of these. If it is determined the infant requires a respirator for breathing, he will be transferred to Fresno, California, for care, otherwise most infants are treated in the unit at Memorial Hospital. It might be noted that the parents of infants who are transferred have a support group in Fresno. All Cesarean section babies are observed for 6 to 12 hours and then transferred to one of the normal nurseries if no complications occur. If complications arise, they are retained in the SCN for as long as necessary. For those babies admitted immediately to the SCN often the parent has had time to glance at the baby and learn the sex, but admission is often quite prompt or urgent following delivery. The usual periods of parental examination and bonding have been aborted.

Once in the SCN the infant will be examined by the physician and any necessary treatment or emergency care will be initiated. This may entail periods that range

from 30 minutes to several hours of immediate care. During this time the parents are not present, although the nursing staff will attempt to keep the family informed of the progress and condition of the infant. Once the infant is stabilized, the father will be able to gown and come into the nursery to see his infant. Usually he is not able to hold him due to on-going treatments, tubes, oxygen, and incubators. Generally the mother is unable to be present, for she may still be in the delivery room or recovery room under care. At this time, she may have merely seen the baby and been informed of the sex. Often there has been no physical contact.

Once the mother is able, she is encouraged to visit her baby in the nursery. She will be required to wear a hospital gown. Special care, gavage feedings, and medical procedures may prohibit her from holding the baby for weeks. Most often she has been precluded from feeding and bathing also. Since she has not been taught these special procedures for handling, and visits may conflict with treatments and procedures, many mothers have experienced concerns of uneasiness about holding and caring for their baby. Even mothers who have had other infants often find themselves unprepared for the care of this infant in the SCN where care is difficult and different.

Numerous articles in research have covered the pros and cons of early attachment and bonding (Barnett, Leiderman, Grobstein, Klaus, 1970; Klaus and Kennel, 1970; Klaus,

Jerauld, Kreter, McAlpind, Steffa, and Kennel, 1972; Ross, 1980; Vietze and O'Connor, 1979; White, 1982) but it is generally considered that both the mother and infant have a definite cybernetic effect on each other during the early weeks and months after birth (Bakerman and Brown, 1977; Blehar, Lieberman, and Ainsworth, 1977; Heifer and Wilson, 1982). If a new infant is unable to respond physically as in nursing, either by breast or bottle, or emotionally as in being quieted by the mother, definite feelings of inadequacy and even guilt begin to emerge. One must also remember that parents are often also dealing with the uncertainty of the baby's prognosis and even life. They often do not feel that the baby is theirs and that others are better qualified to give care to the infant.

The parents at Memorial Hospital demonstrate various levels of parental development. These parents progress through the usual developmental stages as outlined by Kubler-Ross (1969). In essence they mourn the death of a dream, or the loss of a healthy child. The shock, denial, sadness, grief, and anger must proceed the adaptation and reorganization necessary for establishing a meaningful relationship with their new infant. These stages may be of various intensity and varying lengths of time.

In spite of the fact that even though only some of the infants admitted to the SCN will have long-term and permanent problems, the presence of the threat itself is enough to require most parents to rethink their relationship

and proceed through different developmental tasks (Kaplan and Mason, 1960; Sherman, 1980). These tasks then are different than those they would experience with a normal delivery or a non-affected baby. For parents who have a child in the unit, the timing of information, considering their developmental stage is essential. When the parents exhibit a developmental non-readiness and it is coupled with the inherent fear of the equipment and the possibility of infant harm looms, it is found they have major problems in developing a healthy parent-infant relationship.

There are numerous discrepancies in the situation of high-risk babies and parents at Memorial Hospital. The nursing staff is giving the neonate care, but often they are themselves stressed from the same situation as is the parent. Feeling of both frustration and ambivalence, along with guilt are also common among the contact staff (Sherman, 1980). Contradictory feelings of relief and guilt in the parents may not coincide with staff feelings which may range also from anxiety to relief. The usual joy of parenthood is often not experienced and well meaning staff, friends, and family unintentionally elicit even more guilt by their wishful positive comments and attitudes. This often comes at a time when the parents are feeling only anger and anxiety. Time for personal care and attention is often omitted for the high-risk mother where in fact she may be having a difficult time of recovery also. The

father is often called on to fill all the needs of mother, baby, home, and he may be overwhelmed with responsibility.

At this time at Memorial Hospital only the nursing staff and medical staff provide information and care. If there is a question of procedure, the parents may not feel qualified to ask or in fact they may fear their infant may be the object of reprisals from irate staff. Often staff are not able to give concrete answers, yet the various opinions can cause marked confusion in the parents when they compare answers and interpretations.

The difficulties that have been encountered in providing specific care for high-risk infants are numerous--some legitimate and some questionable. By virtue of the fact of the hospital rules, which are governed not only by infection rates, but legalities and the accreditation board, many parents feel excluded from their newborn. By excluding immediate family members such as siblings and grandparents, the family nucleus remains artificial until the premature or high-risk is discharged. Even parental access must be contrived once the mother has been discharged, for special trips must be scheduled for visiting, and these will vary depending on distance, other commitments, sitters, and transportation. The rules of gowns and masks, utilizing hospital equipment and having the babies' supplies all furnished often leaves the parent the impression of non-possession of their baby.

In giving information parental readiness varies as mentioned earlier, and one must be sensitive to correlate the needs of information and education to periods when it will be receptive. Even then time for questions, information repeating, and new updates with different perspectives are necessary. The educational level of parents has varied, and often these new practical and emotional tasks are as difficult for those with high degrees as for those with lower educational levels. Individual parental capacities vary considerably. If they have a first premature, it may matter little that there have been other healthy babies, and it cannot be assumed they are familiar with the care and instructions. Giving information to the parents without having them feel overwhelmed or left in ignorance has been difficult.

Other difficulties involve the mere implication of having a baby in the SCN and have varied from parent to parent and from family to family. Full or part-time employment and the length of maternity leave has compounded the problem for some mothers who are not full-time homemakers. The parents' responsibility to other family members and the degree of independence of siblings have definitely influenced attitudes toward this extra-care baby. The availability of a support system of this family, as relatives, friends, and agencies which will be needed for immediate and long-term care varies and is often a difficult problem for our parents and staff. Individual attitudes are

affected by the age of the parents and whether this was a planned or unplanned pregnancy. Single mothers and ethnic customs all give added problems for some parents.

Last, but not least, expenses incurred, whether private, personal, or third party payments, may have various implications in how parents have responded to past information and education. One of the most impressive difficulties is in evaluating the severity of the newborn's illness. Often the very severely ill child is blessed with parents that are actively involved and the infant's optimum performance can be expected, while one slightly affected infant may suffer for lack of appropriate and maximal relationships.

It has been found at Memorial Hospital that difficulties arise in a program where the parents' education must depend on the availability of current staffing. When the parents most feel a need, there is often a loss of contact with staff because of assignment changes and days off. A major factor appears to be time allotment. For even though the nurses are genuinely interested and counseling of parents is considered vital, the immediate demands of a sick infant must still be met first by the nursing staff.

The people affected by this problem range from staff and family to parents and infant. Long-term effects are felt by family and parents in feelings of competence with this new baby. Failure to thrive (FTT) babies have been

reported in unusually high proportions of high-risk births (Fanaroff, Kennel, Klaus, 1982; Ross, 1980; Shaheen, Alexander, Truskowsky, Barbero, 1968). Abusing parents are most often parents who have had a child they perceive as different (Klein, Stern, 1971), and certainly a newborn who has a precarious beginning fits into this realm.

Often the nurses and medical staff have felt frustrated because of inability to deal with situations they know are vital and important. Parental attitudes with the infant and other family members have ranged from neglect to overcompensation. Long-term effects in mother-child relationships are common (Ross, 1980; Sherman, 1980). It has been observed that the quid pro quo relationships between mother and child are affected. Infant response is often less than desirable. New mothers who already have felt betrayed because of a less than healthy infant, find it difficult to keep responding to a child who does not reciprocate. This may last up to three months. This ability to engage in reciprocal interactions is a vital part of developing an attachment. Most babies are active participants in the molding. Responses elicit responses but in the case of the high-risk infant energies may be diverted for the more practical matters of breathing and eating.

Another person deeply affected by the problem is the husband. Husband's feelings may be even more in jeopardy since the mother-child dyad may in fact be even stronger

and last for a longer period of time leaving the father feeling even more left out. Others involved include the medical team who will often feel vulnerable and frustrated because of their inability to treat the infant or create a change in the situation.

The practical aspects of additional costs at a time when finances are already strained have worried our families and altered energies that could otherwise be used for emotional involvement. Worry over current bills, loss of the mother's income, and added drains for medical expenses and future rehabilitation have been general concerns. The toll on the mother's energies have often been much greater than expected and this has left less time and energy for husband and other family members. It might be noted that the self-esteem of siblings is often adversely effected by a chronic disease in a sibling family member (Pillitteri, 1981).

The problem to be solved by this practicum is that parents of high-risk infants at Memorial Hospital are unprepared for the physical and emotional role demanded of them with their special care infant. Because of the individualization of high-risk infants, parents are affected in varying levels and degrees and at various times and with varying problems. Because of this variety and with constraints of time, it has been difficult for the general nursery staff to prepare parents to feel competent in the new demands of high-risk parenthood where not only physical

and emotional care is required but a foundation for a healthy mother-infant relationship is so vital.

B. Evidence of the Problem

The evidence that this problem exists at Memorial Hospital can be documented by several factors.

1. The Obstetrical Medical Staff polled at an Obstetrical Staff meeting showed a majority were concerned about less than optimal mother-infant relations.

2. A majority of pediatricians from Bakersfield, California polled individually agreed a program was needed for mothers who have infants in the high-risk nursery at Memorial Hospital.

3. Statistics (Bensel and Paxson, 1977; Elmer and Gregg, 1967; Fanaroff, Kennell, and Klaus, 1972; Fomufod, Sinkfore, and Louy, 1975; Hunter, Kilstrom Kraybill, and Loda, 1978; Klein and Stern, 1971; Lynch and Roberts, 1977; Shaheen, Alexander, Truskowsky, and Barbero, 1968) show failure to thrive and abused babies have a disproportionately high number among high-risk infants.

4. Three marriage and family counselors from Bakersfield, California whose practice concentrates on young families agree that many of their clients lay later problems in parental relationships to problems originating with the birth of a high-risk infant.

5. A written poll was taken from a random sample of six mothers who delivered a high-risk infant in Bakersfield,

California in the last two years. Four of the six had no education program in the physical needs of the infant and stated they felt there was a need. All six had no support for themselves and voiced a need. Six of the six had no help in dealing with infant emotions and cues and said it would have been helpful.

C. Causes of the Problem

Analysis of the problem shows that parental information, even if given, is often given out of sync with the attitude and stages a parent is in after the birth of a less than healthy baby. Research shows that parents must generally progress through developmental stages often similar to those of Kubler-Ross's (1969) sequence in death and dying or Drotar's (1975) adaptation and, finally, reorganization.

Often, parental interactions may be distorted and negatively influenced by the infant's unpredictability or difficulty in interpreting clues (Campbell, 1977; Coll, 1977; Minde, Ford, Cellhoffer, Bourydis, 1975), lengthy separation at birth (Barnett, et al., 1970; Klaus, et al., 1972; Ross, 1980), or emotional crises (Benfield, Leibs, Reuter, 1976; Choi, 1973; Drotar, Baskiewicz, Irwin, Kennel, Klaus, 1975; DuHammel, Lin, Skelton, Hantke, 1974; Kaplan, Mason, 1960).

Nurses in SCN often are able to care for the babies, but they have not been trained to teach parents or

demonstrate their skills to others. Counseling and communication skills have only recently been incorporated as part of the nursing curriculum in nursing schools, so many of the older nurses feel unqualified in this area. Social workers who are available at the hospital are often not prepared to actually understand the care of the high-risk baby, and they feel uneasy in critical care areas.

Often the lack of past solutions has generally been laid to lack of funds for an individualized program or lack of individual department responsibility. Whether such a project would be within the realm of social services, nursing or discharge planning has never been defined. There has been no apparent documentation of the need until now, and no department has taken the initiative prior to this due to funding.

Another cause arises from lack of time. Those nurses who have the skills find the job very time consuming, although rewarding. Most often, the nurses have more than one infant for whom they are responsible for administering care. It may be impossible to give undivided attention to parents when they need it if care is necessary for another infant. Parents often feel they cannot wait for answers and help, yet nurses must work on a priority system and even in a Special Care Nursery where counseling in parent care is considered critical, the immediate demands of a sick infant must still be met first.

D. Related Literature

There has been an ever-growing awareness of emotional and relationship problems in the high-risk and premature infant since Bowlby's first review of research in 1951. Often the solutions and remedies were elusive or not readily available within the confines of a community medical center. Since then research has mushroomed by such diverse groups as socialists, psychologists, pediatricians, obstetricians, and nurses. Notable contributions in the area have been by Ainsworth (1966), Bowlby (1951), Kennel (1976), Klaus (1976), and Newton (1955), to mention just a few. Many have become aware of the need to offer these high-risk infants not only the advantages from research that normal infants utilize, but additional attention to relationships and emotional development as well. These infants are often at-risk for developmental delays due to perinatal or genetic conditions (Allen, 1980), and to further complicate these infants with maternal, physical and emotional avoidance and separation can but only compound their problems.

Exaggerated feelings of guilt, fear, failure, rejection, and stress are common (Choi, 1973; Drotar, et al., 1975; DuHammel, et al., 1974; Ferreuram, 1960; Kaplan, et al., 1960; Wortis, 1960) among parents of deviant babies. A study by Choi (1973) also showed higher degrees of depression and anxiety as reflected by insomnia. Numerous longitudinal studies (Bensel, 1977; Elmer and Gregg, 1967;

Fanaroff, et al., 1982; Fomufod, Sinkford, Louy, 1975; Hunter, Kilstrom, Kraybill, Loda, 1978; Klein, et al., 1971; Lynch 1977; Ross, 1980) reflect the effects that may result from these poor mother-infant relationships. Studies demonstrate increases in abuse, failure to thrive, and emotional problems in high-risk infants. Often the parents will be over-protective and anxious and their children may be shy, dependent, and anxious (Coll, 1977). Differences in speech and linguistic patterns in mothers and infants have also been noted (Ringler, Kennel, Jarvella, Novojosky, Klaus, 1980). There have been a few studies that counter most of the research (Bakeman in Blehar, 1977; Ross, 1980) and do not find additional time involving new mothers and their babies to be of any long-term benefit.

The critical time period for maternal imprinting is being examined more closely, but generally it has been found that the maternal attitude along with timing, both for the infant and mother, is a necessary variable in establishing a mother-infant relationship (Coll, 1977; Goldson, 1979; Osofsky, 1976; Ross, 1980).

Mothers must learn to appreciate their infant's potential capabilities (Coll, 1977) and even though the high-risk infant is often not capable of contributing to the relationship at the beginning (Bakeman and Brown, 1977), mothers and fathers must often be assisted in maintaining a one-way relationship until the child has the energies and developmental levels sufficient to respond. Often the

mother will have faulty or negative assessment of the baby's attitude toward her. Many authors have shown how the healthy, full-term infant elicits and promotes reciprocal maternal responses (Coll, 1977; Ross, 1980). In contrast, the sick infant is either more hypotonic or hyperactive, more difficult to arouse and once aroused, more difficult to soothe (Brazelton, 1973; Campbell, 1977; Howard, 1976). This infant's responses are weaker and he is less apt to orient to a face or a voice. He sleeps more, is harder to hold and even more difficult to cuddle. This lack of reciprocal contribution to a relationship is a definite difficulty for many parents. Mothers tend to lose confidence in their ability to care for infants who require extraordinary and specialized nursing care (Sherman, 1980). An unresponsive, sick, passive infant who feeds poorly and from whom parents can derive little pleasure will have little success in engaging his parents (Sherman, 1980). Douglas and Gear (Ross, 1980) suggest that parental contact with low birth weight infants only heightens parental anxiety, but generally infants of mothers with early and extra contact appear to "cry less, smile more, and perform better on developmental testing" (Ross, 1980, p. 50). Parental feeling of non-acceptance of premature babies is a big factor (DuHammel, et al., 1974) in dealing with high-risk parents.

Klaus and Kennel (1970) found that affectional ties can be disturbed easily and may be altered permanently.

Even relatively minor illnesses in the immediate newborn period appear to alter the relationship between mother and infant. Continuation of support to the mother so she will touch and provide increasing care for the baby is important during the hospital period. Klaus and Kennel (1970) also suggest discussion time with the mother about her feelings and worries.

Allen's (1980) study found that early intervention groups that focused on the mother-infant relationship made gains in maternal responsiveness, infant comfort and interaction; these infants also improved in levels of development. Kennedy (1973) also found that positive orientation to the baby can be aided by increasing pleasant mother-infant interactions and decreasing the unpleasant ones. This may be accomplished among others by concrete suggestions and demonstrations of the feeding process along with appropriate reassurances about expressed concerns. In addition to providing provisions for the mother and baby to become acquainted under less stressful conditions, Kennedy suggests guidance for the mother in information gathering and help in interpretation of the infant's negative responses.

Barnett, et al. (1970) and Klaus et al. (1970) have found from their research that it is possible to introduce mother into the premature nursery without clinically endangering the infant or disrupting the organization of care. All but 2 of the 13 mothers responded favorably when

invited into the nursery to handle their infants in incubators. Minde's (1978) studies indicate that mothers of premature infants who have the opportunity to meet with each other along with guidance from an experienced nurse-counselor visit their infants more frequently, interact more with them during their visits, and feel more competent about their general care-taking role than mothers who do not attend such group meetings. These same group meetings seem to ease mothers' hesitations to touch their infants. Minde also believes group meetings could be beneficial because they attenuate the psychological pain associated with the crisis of having a pre-term baby.

Sherman (1980) states that most investigators agree that the ability of people to maintain psychological comfort depends not only on the intrapsychic resources but also on special environmental supports. She sites recent reports that indicate that parents of sick infants who have received additional emotional support behave differently with their infant and that the developmental courses of the infants are affected positively.

It appears clear, from the perspective of many disciplines that the maternal and high-infants' relations may be in jeopardy. Positive results from timely intervention have been reported although few statistical longitudinal studies have been performed. Even without scientific evidence of long-term improvement, most authors suggest early intervention. Part of the problem in obtaining scientific

validation is the question of how to incorporate the numerous variables that would have to be considered in the long-term observation (Allen, 1980; Minde, 1975, 1978).

Chapter III

Anticipated Outcomes and Evaluation Instruments

A. Goals

With the advent of increased technology, more high-risk infants are being admitted to the Special Care Nursery at Memorial Hospital, and these parents are finding themselves challenged in providing the physical and emotional care necessary for their infants. The major goal of this practicum was the development of a program for support and education of the mother of a high-risk infant. A second goal was the institutionalization of the program. After implementation and evaluation of the solution strategy, the proposed project was to be presented to the Memorial Hospital Medical Board for inclusion in the current hospital policy.

B. Terminal Performance Objectives

The objectives were evaluated by the mother's response to the evaluation tool, along with increased skills as demonstrated to the author in the mother's caregiving to her infant.

Objective 1

Mothers of high-risk infants were to increase their awareness and competence in responding to the specific

areas of physical need for their own infant. They were to indicate an increased awareness in recognizing and responding to the current emotional needs of their own infant. Along with this, the mother was to show an increased awareness of the importance of a strong parent-infant relationship. After participating in an individual program of three hours, eight out of ten mothers with infants in the high-risk nursery were to score at least 80 percent on the evaluation tool in questions that measure this area.

Objective 2

Mothers of high-risk infants received counselor support for themselves while in this program. Of those included in the program, eight out of ten were to recognize support was available by responding positively to 80 percent of the questions dealing with parent support on the evaluation tool.

Objective 3

Mothers of high-risk infants who perceived a need of peer support were to indicate support was available after participation in the parents group. Of the mothers who participated in this group, eight out of ten were to respond positively to 80 percent of the questions dealing with peer support.

C. Evaluation Instrument

The evaluation instrument (Appendix B) was designed by the author to reflect parameters in support and education of the high-risk mother. This 28 question tool measured in three areas:

1. Counselor information to the mother included the physical and emotional needs of the infant, and the information to the parents on parent-infant relationships. These were reflected in items 1, 2, 5, 6, 7, 9, 10, 11, 12, 13, 14, 15, 17, and 23 in the evaluation tool.

2. Counselor support to the mother herself was contained in items 3, 4, 8, 16, 18, 24, and 25 of the evaluation tool.

3. Response to peer support was evaluated in questions 19, 21, and 22 in the evaluation tool.

Items 20, 26, 27, and 28 were not tabulated for responses in this practicum report.

Data was computed on the scores of the evaluation tool utilizing ten participants. A "no" response was valued at 0; "somewhat" a value of 1; and "yes" a value of 2. No response received a zero value. The instrument was hand tabulated using raw data scores. They are reported in each of the three areas.

Counselor information to the mother carried a positive response of 28 points total or 100 percent. Counselor support to the mother herself carried a total possible positive

response of 14 or 100 percent, and responses to the peer support was a total of six points or 100 percent.

For interest only responses of individual questions were tabulated using similar demographic data as age of mother and number of children. Example: of the mothers in the 20 to 25 age group, x number responded positively to needing more help; in the 30 to 35 age group, x number responded positively to needing more help. Of first mothers, x number viewed they needed more help; mothers of two children, x number responded they needed more help.

Open-ended questions were analyzed by inductive analysis for trends and clusters.

The instrument was filled out by the mother of a high-risk infant in the Special Care Nursery after completion of one to three hours in the counseling program. This was to allow for inclusion of the majority of the mothers, for most of the infants had an admission of at least five days. The program ran for two months with a-proximately 24 participants--ten of which participated in the final evaluation phase. All evaluation responses were anonymous and were returned to the nursery desk.

Each area carried an 80 percent acceptable level of performance to meet the objectives of this practicum. This was to be accomplished by eight of the ten participants who completed evaluation.

Evaluation of the second goal relied on Memorial Hospital's Medical Board recommending inclusion of the program as a continuing part of the hospital policy.

Objective	Evaluation	Level of Expectation
While in the program:		
1. Mothers of high-risk infants received information to include the physical and emotional need of the infant, along with information on parent-infant relationships.	1. Pulskamp Evaluation Tool Items 1, 2, 5, 6, 7 9, 10, 11, 12, 13, 14, 15, 17 and 23.	1. Eight out of ten participants will respond favorably to at least 80 percent of the item scores.
2. Mothers of high-risk infants received counselor support for themselves.	2. Pulskamp Evaluation Tool Items 3, 4, 8, 16 18, 24 and 25.	2. Eight out of ten participants will respond favorably to at least 80 percent of the item scores.
3. Mothers of high-risk infants who participated in the Parents Group received peer support.	3. Pulskamp Evaluation Tool Items 19, 21 and 22.	3. Eight out of ten participants will respond favorably to at least 80 percent of the item scores.

Chapter IV

Solution Strategy

A. Possible Alternative Solutions

Intervention programs for high-risk infants generally have two primary focuses of therapeutic activity. Many traditional programs emphasize direct educational/ developmental stimulation of the child (Allen, 1980). There are those that train parents to assume the therapeutic role, and those dedicated to the enrichment of the parent-infant relationship (Allen, 1980; Bakeman, 1977). Those programs that deal with any of the parental factors as their personal mental health, infant perceptions, ability in child care or attitudes have been found to be more effective than sole stimulation of the infant (Bernard, 1981).

Traditionally the major emphasis of programs for mothers of high-risk infants incorporate one aspect of support. These programs generally emphasize either early mother-infant contact or family information and discussion groups. Early intervention programs now used extensively often consist of special group education and group discussion for parents. In a related strategy for this problem, DuHamel (1974) found that early intervention with parents may help parenting behaviors. He now contacts parents of

premature infants directly and invites them to one or more special discussion groups. Mahan (1981) emphasized the relationship between parent and infant in appropriate instructions to families, while stressing the positive effects of their relationship. The reason for rejection of this sole intervention is that the need for instruction to the families may not emerge uniformly and the "readiness" of each mother for group discussion certainly may not emerge initially (Buscaglia, 1975; Featherstone, 1980). In a group discussion with parents at different stages it is difficult to present material beneficial to all stages and meet individual needs.

Video tapes of how to care for high-risk babies often miss the point of what is most needed by some, while it may be redundant or irrelevant for others. Mothers who have a high-risk fragile baby often are unable to learn by watching demonstrations. Hands-on learning is vital for the self-confidence they need before being expected to take the baby home and administer the care themselves. Often there is a sense of depersonalization in video education that may be over-empahsized by these parents with severe emotional needs of their own. High-risk infant needs are very individual and the timing needs of each parent are also very unique. Structured video programs or prestructured educational programs often do not meet needs that are perceived by parents as the most pressing for them. This type of intervention is non-personal and for this reason this intervention is

rejected.

It is difficult to teach mothers about their babies' moods and cues from a program utilizing other babies, books, or films. Klaus, et al. (1972) believed differences in maternal attentiveness and responses to their babies may in turn have a powerful effect on the maternal interaction with infants and consequently later development. In Blehar, Lieberman, and Ainsworth's 1977 study, maternal behavior associated with positive infant responses were characterized by the mother's sensitivity to behavioral clues. These clues need to be personalized to the individual mother and baby, and any other discussion will require it to be too general.

Some programs involve nursing staff training and staff intervention with parents of high-risk infants (Caga and Muer, 1979). This appears to work for periods but heavy turnover, varying personalities, and differences in attitudes, along with added job responsibility for the staff may in fact make this solution less feasible at Memorial Hospital where staff is often unstable and meager. The effects of having one person as a intermediary would also be lost.

Benefield, et al. (1976) believe an organized family support program to be a prominent part in the delivery of newborn intensive care. Studies conducted by Minde (1978) show that only after parental feelings of fear, guilt, and depression have been shared is it possible for parents to

begin to comprehend and understand the implications of topics related to the treatment and care of premature infants. But to wait for parents to be emotionally prepared to join a support group before any other intervention is attempted may in fact lose valuable time for the development of infant relationships and care. For this reason, the establishment of a support group alone was rejected.

New programs are developing rapidly. From other research it has been demonstrated that mothers, who do not have their own needs met, find it difficult to give time, attention, and care to their high-risk infants.

Research findings suggest several programs that aid the infant and/or the mother. For this project, then, several of these programs have been incorporated into a single program with one administrator for mothers of high-risk infants.

B. Solution Selected

This author initiated a three-pronged approach in providing the mother of a newly delivered high-risk infant with information and support. The program was developed for mothers whose delivered babies were admitted to the high-risk nursery at Memorial Hospital over a two-month period. Only those babies with anticipated stays of 72 hours or longer were to be included in this program. Cesarean section babies that were admitted for observation of 12 hours or less were not included, while those admitted

for longer care were included. All other admissions, regardless of the diagnosis, were involved after obtaining parent's permission. A two month period of 20 or more participants was anticipated. A major problem that developed, however, was coordinating the last counseling session and administration of the evaluation tool. Mothers were often discharged in 24 hours, and even those staying longer were hospitalized a maximum of three or four days. When the mothers were discharged after 24 hours, the baby would remain under care in the nursery. Even with prescheduled meetings, for continued counseling sessions, some of the mothers were lost. Often there was a conflict of time schedules between the counselor and the mother. About 10 of the scheduled 20 visits were successful. Because of this early termination, the evaluation instrument was not completed by over 14 mothers. The majority of these mothers had been involved in the program for one to three hours, but for lack of a formal evaluation, were not included in the final figures.

The mothers were met by the author as soon after delivery as possible, but not later than 48 hours after delivery. This allowed for non-coverage on weekends. Initial sessions consisted of an explanation of the program and a verbal consent for participation. This was followed by a non-structured verbal interview which covered areas of maternal perception, condition of the baby, parenting, and care-giving skills that were present, along with areas of

concern and need if these had been developed. The Interview Tool (see Appendix A) was given to the mother in the first several mothers, letting her fill it out on her own. This procedure was modified to include a general discussion utilizing the Interview Tool as a guideline for the first session for the remaining mothers. Through this verbal exchange, it was easier to convey the idea there were no "right" answers and more information and areas of concern were elicited by the counselor. One mother who responded to the written interview that she had no concerns in holding her baby admitted later in the verbal discussion that she in fact did have some concerns about holding her baby. For this reason, the interview became a verbal discussion and a part of the counseling sessions.

Utilization of the interview tool continued to be difficult. It was usually conducted in the mother's room, and there was a conflict in finding an optimum time after delivery when the mother felt physically able and interested in participating in the Interview Tool (see Appendix A). The education and counseling session--if conducted in the mother's room--was often in conflict with family visiting, for there are open visiting hours except when other babies are out with their mothers. Even when visits were prescheduled by the counselor, interruptions included phone calls. Nursing activities also caused an occasional priority.

Two methods were tried to ensure maximum conditions for an interview. The first was to have family members present for the interview, if they were visiting at that time. This appeared to inhibit the mother in discussing areas of concern and anticipated problems. If the visitors were asked to remain outside for the interview, the interview seemed rushed. The sessions that took place in the nursery were more intimate, with fewer distractions, and a better rapport developed.

The Interview Tool (see Appendix A) needed to be utilized again once the mother actually came to the nursery. Often what the mother expected to be of concern was not a concern, and new areas of anxiety developed. These new concerns were often reflected in laboratory work and values, feeding schedules, weight gain and loss, and questions concerning equipment and supplies that would be needed when the baby was discharged. Often, too, only after a second counseling session and conversation, when some rapport was established, did many of the real concerns and fears surface.

Through the discussions, along with aid of the Interview Tool (see Appendix A), it was possible to identify areas that needed to be incorporated in the mother's individual program. These areas were evaluated by the counselor for priority and inclusion in the following sessions with this particular mother. Areas of negative attitudes and anticipated difficulty were noted so those concerns were

primary topics and focus in the sessions to follow. These sessions consisted of one to three hours, while several were four to five hours.

The program involved some time given to mothers who had babies readmitted for jaundice of their newborn. Although there were often two to three admissions per week, contact and instruction to these mothers was usually fortuitous. Admissions were from the pediatrician's office and the hospitalization depended on the daily laboratory values. In addition, the baby frequently would be discharged before the mother could be contacted. Those who were involved in the program were usually present for one session including the interview and some education. Evaluations for this group were not administered.

The Program

Area 1

This phase included information given to the mother in the specific areas of need drawn from the completed interview tool (see Appendix A), current condition of the infant, procedures being performed and immediate concerns the mother may have had regarding her infant. Information regarding the infant cues and parent-infant relationships were informally given during these sessions to assist the mother in responding to the emotional needs of her infant. The importance of a strong parent-infant relationship was

stressed. Time for practicing the skills under supervision was included, often having the father involved also. The mother cared for her own baby during these sessions as much as possible.

Area 2

The author assisted in support and skills for the mother in dealing with the birth of this special care infant and the many reverberations it had. This was accomplished by allowing the mother to verbalize and process her feelings of guilt, fear, and anger that she had toward this infant at that time. This counseling was incorporated during the mother-infant contact time, with two having discussions at other scheduled times. Often, these discussions involved personal aspects of the mother and her own individual concerns.

Area 3

Outside of the one to three hours for counseling and education, parents with high-risk infants were invited to join an informal parents' group meeting weekly over coffee after evening visiting hours at the hospital. The agenda for this group was to be informal and consist of peer support and expression of feelings and concerns regarding their infant. Printed matter and community resources that may have been beneficial for continued help was available. It was planned that those parents initially not ready for a

group were to be invited to join at a later date when they felt ready, even if the infant had been discharged. The group was to supply new parents with peer contact and support, as often these parents are a major resource for each other for they can often convey and share feelings and concerns unlike any other. The group was to mature and continue on its own after this program. There were at the most three parents during most of the weeks of the program. Even though each parent voiced a desire for a Parents' Support Group, the few numbers seemed to prevent initiating a group at Memorial Hospital. Referrals were given to each parent for another local group in Bakersfield. None of the parents became involved.

The incorporation of the three areas of parental need in a single hospital-based program was to most effectively prepare mothers for the role in caring and relating to their high-risk infants. It would best utilize professional resources in caring for this particular group at Memorial Hospital. Presentation of the program was to be made to the Memorial Hospital Board for continuation and funding after the two month program. Before this was accomplished, a new position was created and is being developed that has many of the same objectives.

Chapter v

Results, Conclusions, and Recommendations

Presentation and Analysis of Results

There were two goals for this practicum. One was to develop a program for support and education for the mother of the high-risk infant. A second goal was the institutionalization of this program.

The program was presented and evaluation data was collected. Evaluations were tabulated from 10 mothers over a two-month period. Circumstances of these lower than projected returns will be discussed later in the analysis section.

Objective 1

Mothers of high-risk infants were to receive information to include the physical and emotional needs of the infant, along with information on parent-infant relationships.

After participation, eight out of the ten mothers who had infants in the high risk nursery scored 80 percent on the evaluation tool in questions that covered the area of increased awareness in recognizing and responding to current emotional needs of their own high risk infant. The original program that proposed three hours of individual participation for mothers of high-risk infants was modified in some

cases due to early parental discharge from the hospital. Six of the counselor-mother contacts averaged between one and two hours, two contacts were three hours, and two were over three hours.

The evaluation also measured increased awareness and competence in responding to specific areas of physical need for their own infant. This was observed by the counselor also in the mother-infant interactions. Ability and ease of handling, when feeding and diapering the infant greatly increased.

This would be a reflection of the research in which Kennedy (1973) stated that positive orientation to the baby can be aided in increasing pleasant mother-infant interactions. In accordance with Kennedy (1973), as well as this counselor, this was accomplished by concrete suggestions and demonstrations of the feeding process along with appropriate reassurances about expressed concerns. Also in agreement with Kennedy (1973), this program found that with guidance for the mother, the parents were better able to interpret the infant's negative responses.

Results suggest, as did Sherman's (1980), that mothers have a lack of confidence in their ability to care for infants who require specialized nursing care. Obvious feelings of parental non-acceptance of premature babies in dealing with high-risk parents (DuHamel, et al., 1974) was evident in only one of the cases in this practicum.

Objective 2

Mothers of high-risk infants received counselor support for themselves.

Mothers of high risk infants were to receive support for themselves while in the program. Responses indicated that this objective was not met, as only three of the ten mothers responded positively to 80 percent of the questions in this area. Eight of the ten responded positively to 50 percent of the questions. Of the seven mothers who did not respond at the 80 percent positive level, none responded negatively, for they merely left this area unanswered. For these seven mothers there was a total of 18 unanswered questions out of the total of 49 in this area or 36.7 percent was left unanswered by eight mothers. An unanswered response was given no numerical value the same as a negative response, but this may reflect a different attitude.

This objective, although not met, would substantiate the findings of Klaus and Kennel (1970) that state discussion time with the mother about her feelings and worries is of vital importance.

Objective 3

Mothers of high-risk infants who participated in the Parents' Group received peer support.

Mothers of high-risk infants who perceived a need of peer support were to indicate they received support after participation in the Parents' Group. This objective was

not met. With so few participating parents at one time, an in-hospital Parents' Group never reached a functional level. A city group for high-risk parents was used as a referral and alternative. Information of meeting times and places was supplied, but none of this project's parents became involved.

Although Sherman (1980) states that the ability of people to maintain psychological comfort depends not only on the intrapsychic resources but also on special environmental supports, this program found that the parents generally were not ready or willing to make the commitment to reach out for community support in the first weeks. Perhaps a variance in developmental levels of the parents that participated in this practicum displayed they were not yet ready for this particular developmental task demonstrating a definite difference in acceptance levels as outlined by Kubler-Ross (1969) and Kaplan and Mason (1960).

The first goal was to develop a program for support and education for the mother of the high-risk infant. This was only partially attained because only one objective of the three was met. The mothers felt they received the information and education concerning their infants, but the support group and the mother support did not meet the stated criteria.

The second goal, to institutionalize the program, was met indirectly. At the conclusion of this program, but before presentation to the hospital board, a new position

was created for supervisor of in-service in the maternity and obstetrical area at Memorial Hospital. This professional staff person will provide services for nursing staff and parents in the high-risk area. In light of this, the goal has been met. The final report will be disseminated to the hospital as planned. This information will have value to the supervisor in setting up objectives for the new position. Other areas will be discussed with the pediatricians and the hospital board as planned.

Conclusions

The ten participants reflected mothers who were able to complete the evaluation form. Over 22 mothers were contacted while in the hospital after delivery. Of these, 14 completed the interview tool and were given some information and education regarding their infant in the high-risk nursery. These 14 were given one to three hours of individual education and then 10 of the mothers completed the evaluation tool.

Many of the mothers originally contacted were discharged within 24 hours of delivery. Follow-up phone contact on two of the mothers was through a neighbor or mother, so setting up future appointments at the hospital was not successful. Often the hours of parental visits to the hospital did not coincide with the counselor's available hours, resulting in the loss of several potential participants.

Two mothers had infants transferred to out-of-town university centers. Evaluations were not available from these mothers, although education and counselor contact time was above the average one to three hours.

The mean age of the 10 mothers was 25 years. Other data is reflected in Table 1.

Table 1

Age	Number of Participants	Educational Level	Previous Children
15	1	9th	none
20	1	12+	none
21	2	12/12+	none/one
24	1	12	none
27	1	college grad	none
29	1	post grad	none
33	1	1 yr. college	3
36	1	12	one
x	1	x	x

Questions that were included for information data only are included below (see Appendix B).

	Yes	No	Somewhat	No Response
20. Were there other outside sources who were available?	5	0	2	3

	Yes	No	Somewhat	No Response
26. Were you able to communicate the information to other family members?	4	0	1	5
27. Will you continue to need help at home?	6	0	1	3
28. Should other family members be included in the program?	2	0	2	6

Data on the six positive responses in question 27, "Will you continue to need help at home?" is reflected in Table 2. This was the first infant in the Special Care Nursery for all participants.

Table 2

Age	Education	Previous Children
36	12+	one
27	college	none
24	12+	none
21	12+	none
21	12	one
15	9	none

The mean age is 25 years and the average educational level for this group, that feels they will continue to need help, is 12 years.

The large proportion of "no response" answers could have several explanations: (1) wording of the question may have been ambiguous, or (2) the respondents were not clear or committed to an answer. Because the evaluations were anonymous, follow-up with specific explanations was not possible.

There were three fathers involved in the program. Originally the program was set up for education of the mothers in the high-risk nursery. After the first father asked to be included, the author invited each father for future presentations. Often they had to be scheduled over lunch or evening to accommodate various work schedules. Very positive feedback was given, although evaluation forms were completed by only one father since the other two were not present at the final session.

The level of education ranged from one person in ninth year; two who completed the twelfth year; four with some college; and two who completed college (see Table 3).

Table 3

Education Level	9 Years	12 Years	College
1 no response	1	2	4 with some 2 graduated

From this data it is evident the subjects were above average in formal education. In spite of this above average level, the author ran into several cultural customs and superstitions. Usually these were innocent beliefs that involved care of the hair, or garment pressure on the umbilicus to prevent hernias, but some threatened the welfare of the infant.

One mother had a previous baby who was "mean" and she questioned if this newly delivered, unwanted and unplanned child would also be "mean." Another superstition hampered a mother from holding her baby in the special care nursery. She feared the umbilical cord falling off while she held her baby. After some discussion, the mother admitted "if the cord falls off and falls on the ground, the baby will pee her bed the rest of her life." She was discharged after 48 hours without visiting her baby in the nursery. Her fears were dealt with by conversation and education.

Time and attention was directed to making the mother feel comfortable both with the counselor and infant. The mother displayed trust in the counselor by virtue of her confiding this superstition, yet the counselor was not able to circumspect the mother's beliefs even though the mother "knew they were silly." From this it should be pointed out that beliefs must be respected, and often the evolution of change occurs over a long period no matter how well intentioned the intervention. This mother resisted repeated

attempts to help her acclimate to holding and feeding the baby while in the nursery for seven days after her own discharge. The infant was low in birth weight but had no other complications as far as medical complications that would preclude the mother from handling her infant. This mother and infant referred to the Public Health Department for further follow-up care.

The evaluation questions dealing specifically with counselor support (Evaluation #24 and 25, see Appendix B) reflect that six of the ten mothers did not respond positively to having received support for themselves during this program. During the interviews and sessions with the mothers, another trend was established. Many of the mothers expressed a "let down" feeling and a definite sense of lack of personal support. All but one of these mothers had a husband, and some had parents living in the area. Many of the mothers felt their own needs were not being met even with some support offered in the program. These mothers felt that they needed more time and attention discussing their feelings about themselves as a person and individual. Areas most often mentioned as personal concerns were appearance, energy level, capability, marital relationship, money, and concerns about returning to work. The consensus of most mothers was that each would need some help once home both for themselves and for the care of the baby (see Figure 2). All of these participating mothers were

given the number of a local organization called "Warm Line" that could be a source of support. It is a local volunteer agency that helps parents over the phone with questions concerning children. Additional referral agencies are then given if necessary.

Conclusions

The program was designed to help mothers of high-risk infants with support and education involved in caring for their infants. The program met one of the three objectives related to this goal. The second goal of institutionalization of the program was indirectly met. The number of mothers actually involved was greater than the program statistics reflect.

Mothers were open and eager for the time and information given to them. Staff was cooperative and readily became involved. Some fathers requested participation in the program and those that could participated.

While the program suffered from deficit of contact time with each mother and conflict of schedules, it continues to be the consensus of participating mothers, nursing staff, father, and this author that there is a definite need for such a program.

Recommendations

The inherent limitation of hospitalized time for mothers after delivery will require that future programs in the

hospital be confined to one of the areas, either education or support of the mother. If the program is utilized primarily as a teaching tool for mothers, other accommodations could be made for the support system. This may include:

1. More personal time for the mother and her individual concerns, i.e., appearance, energy, marital relationships, finances, capabilities, prospects of continuance in career, and areas of diversion by the social service department.

2. Continued individual support for the mother once discharged as in group or individual counseling and support groups. Referrals to the community services from the hospital.

3. Initiate group, infant, and mother programs after the first six weeks when there appears to be a resumed interest in outside activities. The difficulty with this time frame is that the first six weeks of critical bonding and teaching are lost.

4. Encourage phone contact with local support groups or the hospital nursery in the initial days and weeks at home, until other support systems can be developed.

5. Encourage earlier utilization of the Infant Stimulation program for assessment and the Public Health Department for monitoring of care and education.

6. Initiate at-home follow-up programs to supply both support and information to mothers.

Dissemination

A copy of the report will be given to Memorial Hospital Pediatric Board, Bakersfield, California. The nursing staff in the Maternity Department and Nursery Department will receive this information also.

This program was presented at the Mid-Continent Conference in Kansas sponsored by the State Department of Education in March, 1984.

Further dissemination has been scheduled through conferences and panels to local pediatricians, parents, nurses, and nursing students at California State College in Bakersfield.

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Appendices

Appendix A

Interview Tool

INTERVIEW TOOL

Your Name _____ Age _____

Sex of Baby _____ Date of Birth _____ Number of Pregnancies _____

Children at home with sexes and ages _____

_____

Have you previously had a child admitted to the Intensive Care or Special Care Nursery?

_____ If so, when? _____ For how long? _____

I had been to an Obstetrician before delivery. Yes ___ No ___ How many times? _____

I participated in prenatal classes. Yes ___ No ___ Comment _____

I had planned on nursing. Yes ___ No ___ Comment _____

Please check the response that is most appropriate for you and make any comments below.

1. I was sick during my pregnancy. Yes ___ No ___
2. I was worried during my pregnancy. Yes ___ No ___
3. My physical condition now is a problem. Yes ___ No ___
4. I feel very anxious. Yes ___ No ___
5. I have not been sleeping because I have been worried. Yes ___ No ___
6. Compared to most people I worry about my health much more. Yes ___ No ___

Comment: _____

Please indicate your concern about your baby's condition and care you will be giving to the baby, in the following areas:

7. Breathing Extremely ___ Moderate ___ None ___
8. Skin color Extremely ___ Moderate ___ None ___
9. Baby's responses Extremely ___ Moderate ___ None ___
10. Weight Extremely ___ Moderate ___ None ___
11. Sleeping long intervals Extremely ___ Moderate ___ None ___
12. Sleeping too short of intervals Extremely ___ Moderate ___ None ___
13. Breast feeding Extremely ___ Moderate ___ None ___
14. Bottle feeding Extremely ___ Moderate ___ None ___
15. Hearing Extremely ___ Moderate ___ None ___
16. Movement Extremely ___ Moderate ___ None ___
17. Exercise Extremely ___ Moderate ___ None ___

18. Strength — Extremely ___ Moderate ___ None ___

19. Holding my baby — Extremely ___ Moderate ___ None ___

20. Bathing my baby — Extremely ___ Moderate ___ None ___

21. Diapering my baby — Extremely ___ Moderate ___ None ___

Any Comments: _____

_____

22. This is a difficult time for me. — Yes ___ No ___

23. This is a difficult time for my husband. — Yes ___ No ___

24. This is a difficult time for my family. — Yes ___ No ___

Any Comments: _____

_____

For the following questions indicate where you believe you or/child will fall on scale. (Please indicate by placing an "X" on the line.)

25. Feeding my child — Easy _____ Hard

26. Holding my child — Easy _____ Hard

27. Awakening my child — Easy _____ Hard

28. Quieting my child — Easy _____ Hard

29. My baby is too active — Yes _____ No

30. My baby looks at me — Yes _____ No

31. My baby knows my voice — Yes _____ No

32. I worry more than most people — Yes _____ No

33. I need help in caring for my baby — Yes _____ No

34. I usually react calmly — Yes _____ No

Will you have help at home? Yes ___ No ___ If yes, who? _____

Would you be interested in a parent's group evening meeting at the hospital once a week while your child is in the hospital? Yes ___ No ___

Would you be interested in this gorup later on? Yes ___ No ___

Other things I wish to be covered in my program _____

_____

_____

_____

Appendix B

Evaluation Tool

Dear Parent,

Please evaluate the program you received when your child was in the Special Care Unit after delivery, along with the weekly Parents' Group if you participated.

1. I was given information regarding my infant's status and problems. Yes___ Somewhat___ No___

2. This information was helpful in caring for my baby. If no, what was needed? _____
_____ Yes___ Somewhat___ No___

3. The same person was available on a regular basis to answer my questions. Yes___ Somewhat___ No___

4. Having the same person available on a regular basis was important to me. Yes___ Somewhat___ No___

5. I received needed information regarding my infant's physical needs, such as feeding, diapering, and bathing. Yes___ Somewhat___ No___

6. This information was adequate. If no, what could have been added? _____
_____ Yes___ Somewhat___ No___

7. I practiced enough to feel comfortable in giving care to my baby. If no, what did you need more time with? _____
_____ Yes___ Somewhat___ No___

8. A counselor was available when I visited my baby at the nursery. Yes___ Somewhat___ No___

9. I received information regarding my baby's emotional needs. Yes___ Somewhat___ No___

10. It was helpful. Yes___ Somewhat___ No___

11. I feel more comfortable in responding to my baby's cues and emotional needs. If no, explain.
_____ Yes___ Somewhat___ No___

12. I received information regarding parent-infant relationships. Yes___ Somewhat___ No___

13. The parent-infant relationship was important. Yes___ Somewhat___ No___

14. I feel more comfortable in the parent-infant relationship. If no, explain. _____
_____ Yes___ Somewhat___ No___

15. Necessary information was made available. Yes___ Somewhat___ No___

16. The level and timing of information was appropriate for me. If no, explain. _____
_____ Yes___ Somewhat___ No___

17. I received information on how to respond to my baby's cues and moods. Yes___ Somewhat___ No___

18. I felt I received support in giving care to my infant. Yes___ Somewhat___ No___

19. I participated in the weekly Parents' Group. How many times? _____
_____ Yes___ Somewhat___ No___

20. There were other outside sources who were able to help me during this time. Who? _____
_____ Yes___ Somewhat___ No___

21. The Parents' Group did supply support for me. Yes___ Somewhat___ No___

22. I felt I had something in common with the other parents in this Parents' Group. Yes___ Somewhat___ No___

23. I was better able to understand my baby after the program. Yes___ Somewhat___ No___

24. I received support from the counselor. Yes___ Somewhat___ No___

25. This support helped me. Yes___ Somewhat___ No___

26. I was able to communicate the information to other family members. Yes___ Somewhat___ No___

27. I feel I will continue to need help once I go home. If yes, who is available for you?
_____ Yes___ Somewhat___ No___

28. Other family members should be included in this program. Yes___ Somewhat___ No___

Thank you for your time. Please add any comments or suggestions you feel may improve the program.

Your age _____
Number of other children _____
Ages of other children _____
Others in the Intensive Care or Special Care Unit previously? _____
Your level of education ___ ___ ___ ___ ___
8th 9th 10th 11th 12th

College ___ ___ ___ ___ _____
1 2 3 4 post grad.

RETURN IN ENVELOPE PROVIDED OR LEAVE AT THE NURSERY NURSING STATION.